Our Mental State: Addressing the Mental Health Needs of the Community Choices Population

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Executive Summary

INTRODUCTION TO COMMUNITY LONG TERM CARE

The Community Long Term Care (CLTC) program is a Medicaid funded program run by the South Carolina Department of Health and Human Services (SCDHHS). This statewide program is designed to help eligible participants remain at home and avoid unnecessary or premature nursing home placement by offering a variety of home and community-based services.

In 1984, the Centers for Medicaid and Medicare Services (CMS) approved South Carolina's request for a home and community-based waiver for the elderly and disabled population- currently known as the Community Choices waiver[1]. At inception, this waiver began as a pilot project in the upper part of our state serving 659 participants and offering one (1) waiver service- personal care[2]. To date, this program has expanded statewide serving 16,611 participants[3] and offering a variety of services including but not limited to case management, personal care, adult day health care, home delivered meals, nutritional supplements and respite care. To be eligible for the Community Choices program, participants must be 18 years of age or older and meet nursing facility level care.

Problem Statement

As the census for the Community Choices program continues to grow, so do the needs of the participants it serves. According to the South Carolina State Plan 2013-2017 edition, South Carolina has experienced a significant growth of seniors and mature adults in the last few

[1] https://www.scdhhs.gov/internet/pdf/manuals/cltc/Section%202.pdf
[2] Coogan, Mercy "Yes, You Can Go Home: South Carolina's Community Long Term Care Project"
[3] Census data is from CLTC's weekly report from Phoenix. Data is accurate as of February 5, 2018.

decades. In fact, census projections have South Carolina's senior population doubling by the year 2030. Therefore, as our aging population continues to increase, so will the need for long-term care services, both institutional and community-based.

Unfortunately, however, most long term-care programs are not equipped to handle the increasing needs of the participants they serve. Most long-term care programs focus on the physical ailments or conditions of its population while neglecting their mental and psychosocial needs. Studies have shown that to be an effective long-term care program, services must extend beyond the physical ailments and encompass the psychosocial needs of the population it serves.[4] South Carolina is considering shifting to a Coordinated Care model that would ensure all participants served are receiving a full array of benefits.

This study seeks to identify the types of mental health services and/or resources needed to support Community Choice's participants and any barriers preventing accessing to care.

Methodology

The combination of qualitative and quantitative data were used to complete this study.

QUALITATIVE DATA COLLECTION EFFORTS

Participant and key stakeholder surveys were used to gather input from behavioral health professionals and those individuals currently enrolled in the Community Choices program to better identify the resources in use and the barriers preventing access to care.

- Participant Surveys: Participant surveys were the main source of data collection for this study. The study population included randomly selected Community Choices

[4] Mental Health of Older Adults (2017). Retrieved from www.who.int/mediacentre/factsheets/fs381/en/

participants who have received behavioral health services or have a behavioral health diagnosis between the timeframe of September 2015 and October 2016.[5] For those participants who were not competent to be interviewed or give consent, his/her Legally Authorized Representative was interviewed so that their experience and satisfaction are included. Each participant selected as part of the sample, received a letter of introduction to the survey and consent information (see Appendix A). Interviews were conducted by Clemson University's Office of Research and Organizational Development staff using a Computer Assisted Telephone Interviewing (CATI) program. The instrument consisted of 39 pre-coded and open-ended questions and took an average of 20 to 30 minutes to complete. See Appendix B.

- Key Stakeholder Surveys: These surveys were conducted in person and contained 16 open-ended questions to gain insight and direct experiences from behavioral health professionals. Results of the interviews are incorporated throughout the study with direct quotes found in quotations. The instrument used for this study is located in Appendix C.

QUANTITATIVE DATA COLLECTION EFFORTS

Census data and utilization statistics were analyzed. The census data were provided by Community Long Term Care's case management data base, Phoenix. Using the assessment information, those participants who had a behavioral health diagnosis were identified.[6] To determine the number of participants who received behavioral health treatment during the identified timeframe, claims data from Medicaid's Truven system were analyzed. The data set

[5] Medicaid allows providers one year from service date to bill for services. Choosing this timeframe assures that there is complete claims data available for analysis.

[6] Information listed on the assessment is self-reported by the participants and/or their Legally Authorized Representative

searched for those claims in which a behavioral health diagnosis was listed as the primary reason for the visit. By combining datasets, I was able to determine if there was a gap in service utilization. More information can be found in the "Service Utilization" section of this study.

SAMPLE PARAMETERS

The sample size for this study was chosen to guarantee a maximum margin of error small enough to have reasonable confidence in the results. The total population who met the sampling criteria was 3,397 participants. Over the course of three months (November 2017 to January 2018), 168 surveys were completed and 76% of those interviews were conducted with the participants themselves.

Waiver	Population	Sample Size	Maximum Possible Margin of Error
Community Choices	3397	168	+/- 7%

Data Analysis

Given the exploratory nature of this study, no claims of representativeness are made. However, results from this study provide information in three broad categories: demographic variables, service utilization data as well as barriers preventing access to care.

DEMOGRAPHICS

As mentioned earlier, the sample population included randomly selected Community Choices waiver participants who have either received behavioral health services or have a behavioral health diagnosis between the timeframe of September 2015 and October 2016. Demographics of the sample are described below.

GENDER

Female participants comprised most of the sample representing 74% or 125 participants compared to 43 males (24%). These numbers are not surprising and prove to be consistent with national data trends that state the prevalence of mental illness is higher among women compared to men.[7]

AGE

There was a myriad of ages represented in the sample. However, adults aged 45-64 comprised most of sample (47%) followed by mature adults aged 65 and older (41%). The median age of the sample was 61.

DIAGNOSIS

Depression was the most common diagnosis in the sample. Many factors can attribute to this such as experiencing life stressors that come with age (e.g., loss in capacities, decline in functional ability or other health problems); loss of a loved one; or socioeconomic status. Each of these factors can lead to psychological distress in an individual and are not uncommon in the aging population. Unfortunately, further data analysis into this variable was not completed as de-identified data was supplied for analysis.

[7] https://www.nimh-nih.gov/health/statisitics/mental-illness.shtml

SERVICE UTILIZATION

One of the most important findings of this study is related to service utilization. Data shows that 28% percent of the sample attest to receiving some form of behavioral health treatment but a vast majority have not. These are alarming statistics. This section of the study provides data on the types of services used while the next section seeks to identify what the possible barriers are. The table below represents the most commonly used services of the sample.

Types of services Used	Percent who used Service	Percent who say service helped
Psychiatric hospitalization	13%	67%
Outpatient treatment	27%	57%
Medication	67%	50%
Support Group	3%	60%

Medication was identified as the primary form of service utilization. It is not surprising that 67% of the sample sought medication as a form of treatment considering that 89% of the sample has a diagnosis of depression. Antidepressants are most commonly used to treat depression and can be prescribed by almost any physician. Participants in this sample cited neurologists, primary care physicians and other specialists as their prescribing doctor. However, only 50% of those prescribed antidepressants actually said that they work citing "*the medication made the depression worse"* as the main reason for discontinuing use.

Outpatient treatment was the second most commonly utilized service. Participants found that meeting with a mental health counselor in a local mental health center was beneficial to them. A staff member at the Department of Mental Health indicates that *"seeking treatment at Mental Health can be a seamless process and states that most of their outpatient referrals are "self-*

referrals, referrals from family and court orders." There are currently 17 Mental Health Clinics located throughout the state.[8]

Overall, inpatient treatment (psychiatric hospitalization) and support groups seem to be the most effective forms of treatment, but not the most commonly used with only 13% and 3% utilization respectively.

BARRIERS TO TREATMENT

Arguably, one can hypothesize that stigma, shame, embarrassment, or socioeconomic factors play a role in the decision not to seek treatment while others may believe that is more societal factors (e.g., lack of providers; lack of transportation). Some may believe that it is both. We decided to ask the participants in our sample a series of questions related to barriers to treatment and the following table details the results.

Barriers	Percent who report it as a barrier	Percent who think it's a major problem
Having no local services	24%	60%
Transportation	34%	54%
Lack of insurance to cover services/medication types that they need	15%	56%
Long wait lists	21%	46%
Not knowing which services are right for them	45%	42%
Fear of what others might think	12%	45%
Bad previous experience with a provider	21%	52%

[8] History of South Carolina Department of Mental Health

Interestingly, participants in our sample reported that *"Not knowing which services are right for them"* was the biggest barrier to treatment followed by lack of transportation and no local services. Stigma (fear of what others might think) was rated lowest by our participants.

On the other hand, key stakeholders were asked the following questions: *"Where do gaps exist in the system and how do these gaps affect the end user? Are there any gaps that are particularly pronounced based on region?* Their responses are summarized as follows:

- Transportation, housing, and lack of knowledge are the major gaps within the system and these issues vary statewide.
- Prior authorization has negatively impacted treatment. All clients of mental health must be referred from acceptable source. One key informant indicates that "*many clients do not have a primary care physician or access to other referral sources."*
- Need for more therapists and psychiatrists throughout the state.

Indicatively, participants desire to seek help but need a little more education in which service(s) would best meet their needs while also being able to access the appropriate care within their communities.

Participant and key stakeholders seem to agree on the common barriers to treatment—transportation and knowledge gaps. However, with such an alarming statistic related to service utilization, further data analysis was completed to determine possible causes.

The most interesting and probably most important finding is that those participants who utilized behavioral health services do not meet the typical Medicaid beneficiary profile. Over one-half of the participants who received treatment were in the higher payment category of Medicaid-payment category 15. These participants have slightly higher income levels. While

socioeconomic factors were not a determinant for barriers to accessing care, it is indicative that those with higher income levels knew what services were available and were able to access them.

Education levels as well as regions of the state were also explored but the data did not yield any significant factors or trends related to these variables.

Recommendations

This study provided viable insight into the behavioral health needs of our Community Choices participants. The data has proven that there is a gap in behavioral health service utilization among this waiver population that can be attributed to a variety of factors: lack of education about resources and which ones are right for them; lack of transportation; as well as lack of local resources.

While we were able to identify what the barriers are preventing accessing to care, further analysis is needed to understand ***why*** the gaps exist. This study focused on the participants' perspective as it relates to barriers to treatment but did not account for any systemic implications. To implement an effective solution to the problem, the Community Long Term Care (and possibly Mental Health) systems need to be analyzed.

SHORT TERM GOAL

Therefore, it is necessary for Community Long Term Care to complete a full systems analysis similar to what the state of Nevada completed in 2013[9]. The analysis should assess the following:

[9] Marschall, Kelly and Watson, Lia "Comprehensive Gap Analysis of Behavioral Health Services" (2013). Retrieved from www.dpbh.nv.gov/uploadedfiles/04%202013-10-11_BehavioralHealthGapAnalysisReport.pdf.

- Strengths: assets, resources or capabilities that have the greatest impact on the success of our program and its mission.
- Weaknesses: any deficiencies in resources or capabilities or liabilities that hinder the ability of the organization.
- Opportunities: external factors that offer opportunities to benefit the organization (e.g., expansion of services); as well as,
- Threats: external conditions, trends and other factors that could hurt the organization if not addressed.

This study could be completed by Community Long Term Care's current contractors, Clemson University's Office of Research and Development. The scope of this study aligns with the purpose of the contract-- to assist with quality assurance efforts for the department. With the ability to utilize existing resources, I do not anticipate any additional costs to facilitate this work study.

LONG TERM GOAL

South Carolina should consider implementing a No Wrong Door concept. I believe that this initiative will address all issues identified by our participants. No Wrong Door is a collaborative effort of the U.S. Administration for Community Living (ACL), the Centers for Medicaid and Medicare Services (CMS), and the Veterans Health Administration to support states efforts to streamline access to LTSS options for all populations and payors.[10] As indicated in this study, participants desire to receive services but are unfamiliar with what services are right for them and the ability to access such services. Finding and accessing the right services can be a stressful task

[10] No Wrong Door System and Administrative Claiming Reimbursement Guidance https://www.medicaid.gov/medicaid/financing-and-reimbursement/admin-claiming/no-wrong-door/index.html

for individuals and their families at a time when they are most vulnerable. A No Wrong Door system would eliminate participants and/or their caregivers from having to contact multiple agencies to navigate long term care services. A key informant explains that *"we often fail our participants by not networking with other agencies to let them know what services are available and how to access these services."* No Wrong Door offers a person-centered, one-stop coordinated system that streamlines the access to long-term services and supports offered by the public and private sector providers.

Because this initiative is a collaborative effort among multiple agencies throughout the state, support from state leadership, the Medicaid agency, any agencies that offer aging programs and stakeholders (to include families and advocates) is key.

States can claim federal matching funds, known as Federal Financial Participation (FFP) for Medicaid administrative activities performed under the No Wrong Door System and full guidance on how to seek such funding is located here: https://www.medicaid.gov/medicaid/financing-and-reimbursement/admin-claiming/no-wrong-door/index.html. Alabama, Colorado, District of Columbia, Hawaii, and Virginia have all been awarded grants to assist with the implementation of a No Wrong Door System in their state[11].

Overall, adding South Carolina to the list of grantees would increase access to home and community- based services and provide an integrated and streamlined long term care system. Thus, addressing the barriers to treatment identified in this study.

[11] Aging and Disability Resource Centers Program/No Wrong Door https://www.acl.gov/programs/connecting-people-services/aging-and-disability-resource-centers-programno-wrong-door

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APPENDICES

Appendix A Participant letter of Introduction

Appendix B Participant Survey Instrument

Appendix C Key Stakeholder Survey Instrument

APPENDIX A

PARTICIPANT LETTER OF INTRODUCTION

Dear Program Participant:

Clemson University has been hired to conduct a survey of people in the **Medicaid Community Long Term Care (CLTC)** program in South Carolina. CLTC wants to know about possible barriers to engage and receive mental and behavioral health services.

Your name was randomly selected from a list of people who receive services through CLTC to participate in this survey. As we will contact a limited number of people, it is quite important that you participate if you are called. While your participation in the survey is appreciated, it is your choice whether or not you participate. Your decision to participate or not will **no way** affect your services.

Within the next several weeks, someone from **The Office of Research and Organizational Development** at **Clemson University** may be calling you about this survey. The survey is conducted over the phone, and it will not take a lot of time – 20 to 30 minutes to complete. The survey will focus on identifying barriers to mental and behavioral health services and possible. Your answers will help to improve the CLTC program and the services it provides.

You may decide to not answer any questions, and you may stop taking the survey at any time. There is no penalty if you do so. Should you desire, we will eliminate any answers you have given.

The only risks or discomforts to you in this research study is a loss of confidentiality in three circumstances. Nothing that you say will get anyone in trouble and everything will be kept confidential – **except:** 1) **if** you are at risk of serious harm. 2) we might be required to share the information we collect from you with the Clemson University Office of Research Compliance and the federal Office for Human Research Protections. If this happens, the information would only be used to find out if we ran this study properly and protected your rights in the study. 3) **you** wish us to report your answers to someone in authority. Please note that our Office is required by law to report suspected abuse or neglect. **Other than these three situations:**

- **None** of the information that you share will be given to anyone who is paid to help you.
- Your responses will **never** be reported with any identifying information. All of your answers will be combined with others' answers to be reported back to the CLTC program. No one other than the interviewer and the senior researchers will know you were contacted or how you answered. Some of the study findings may be presented in written publications and at conference meetings.

The interviewer you will talk to has **nothing** to do with providing you services. If you have questions about your services, you should contact your Case Manger or Area Administrator for answers.

Thank you. We look forward to talking with you. For general questions, you can contact the Clemson University Office of Research Compliance (ORC) at xxx-xxx-xxxx or irb@clemson.edu. If you are outside of the Upstate South Carolina area, please use the ORC's toll-free number, 866-297-3071.

If you have any questions about this survey, you can call the survey center at **xxx-xxx-xxxx**, and speak to **Tommy Edwards,** or any of the on-site managers**.** You may request a summary of the study findings by contacting your respective SCDHHS-CLTC Area Administrator.

Sincerely,

Justine Gradillas, MSW, CMSW

Director of Program Operations

The Office of Research and Organizational Development

Youth Learning Institute

Clemson University

APPENDIX B

PARTICIPANT SURVEY INSTRUMENT

2017 CLTC Participant Access to Mental Health Services Study

Q.1. Is the Primary Contact or the Participant answering?

1 Primary Contact
2 Participant

Q.2 **SECTION I:** Specific Service Experiences

There are a variety of behavioral health care services that can be provided to help people live a meaningful life. To start our conversation, I would like for you to tell me if you have used a variety of different services for mental or behavioral health care in South Carolina in the past two years. For each service that you have used, I am going to ask you to tell me how well this service met your needs.

Q.3 Have you ever had an inpatient stay (been hospitalized) for behavioral health care?

1 Yes
2 No

Q.4. Please let me know how well this met your care needs.

1 Always met my needs
2 Usually met my needs
3 Sometimes met my needs
4 Never met my needs

Q.5 Have you ever had outpatient care, such as going to a counselor/therapist at a community mental health center, for behavioral health care?

1 Yes
2 No

Q.6 Please let me know how well this met your care needs.

1 Always met my needs
2 Usually met my needs
3 Sometimes met my needs
4 Never met my needs

Q.7 Have you ever had a doctor prescribe you medication for behavioral health care?

1 Yes
2 No

Q.8 Please let me know how well this met your care needs.

1 Always met my needs
2 Usually met my needs
3 Sometimes met my needs
4 Never met my needs

Q.9 Where did you see the doctor who prescribed this medication? Select all that apply.

1 Primary Care Doctor (Family Doctor)
2 Emergency Room
3 Inpatient stay at hospital
4 Urgent care
5 Psychiatrist or Physician at Community Mental Health Center
6 Other

Q.10 If Q7 was other or more than one of the professionals listed, please explain in this space. Please ask the respondent follow-up questions to clearly capture her/his response.

Q.11 Does someone currently prescribe you medication for a mental health condition?

1 Yes. A doctor at a mental health center
2 Yes, my primary care doctor
3 Yes, a doctor at the hospital- ER
4 Yes, a doctor at the hospital- inpatient stay
5 Other
6 No

Q.12 Please let me know how well this met your care needs.

1 Always meets my needs
2 Usually meets my needs
3 Sometimes meets my needs
4 Never meets my needs

Q.13 Have you ever attended a support group for behavioral health care?

1 Yes
2 No

Q.14 Please let me know how well this met your care needs.

1 Always met my needs
2 Usually met my needs
3 Sometimes met my needs
4 Never met my needs

Q. What type of support group did you attend? Where was this group located? Does the participant still attend? NOTE: Location of support group is about understanding what organization hosts the group not where the group is located on a map.

Q.16 Other than the list of services that we just discussed, can you tell me about any other services you have used for behavioral health care? [Probe: For each 'Other' service mentioned, please ask the respondent to tell you what made them seek the service and how effective that service was to meet the needs that they discussed].

Q.17 **SECTION II:** Barriers to Services

Now I would like to talk with you about problems that people might have with getting certain services for behavioral health. There are a number of reasons that people may not receive the assistance they need. CLTC wants to understand why people who need services may not be able to access care.

Please indicate which of the following you believe prevents you or other people from accessing services and the severity of the issue.

Would you say that having no local services available is an issue that affects you from getting behavioral health care?

1 Yes
2 No

Q. How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.19 Would you say that lack of transportation is an issue that keeps you from getting behavioral health care?

1 Yes
2 No

Q.20. How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.21 Would you say that lack of insurance is an issue that keeps you from getting behavioral health care?

1 Yes
2 No

Q.22 How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.23 Would you say that long wait lists is an issue that keeps you from getting behavioral health care?

1 Yes
2 No

Q.24] How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.25 Would you say that not having the right services to fit your needs keeps you from getting behavioral health care?

1 Yes
2 No

Q.26 How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.27 Would you say that fear of what others might think is an issue that keeps you from getting behavioral health care?

1 Yes
2 No

Q.28 How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.29 Would you say that having a bad previous experience with a provider is an issue that keeps you from getting behavioral health care?

1 Yes
2 No

Q.30 [IF Q29=1, then DISPLAY] How severe of a problem do you think that this is?

1 Big problem
2 Medium problem
3 Small problem

Q.31 [OPEN-ENDED] Can you think of any other reasons that might keep you from getting behavioral health treatment? [Probe: For each 'Other' response, please ask the respondent to tell you how severe they believe that the problem is.]

Q.32 Can you think of anything that has made it easier for you or others to get behavioral health treatment?

Q.33 How significant of an issue is access to behavioral health care for your community?

1 This is a big issue - there are a lot of needs that remain unaddressed
2 This is a moderate issue - there are ongoing needs, but services are available
3 This is a minor issue - there are system improvements needed, but they are minor and do not affect the critical health issues of individuals

4 This is not an issue - services being provided are sufficient to meet the needs of people.

Q.34 On a scale of 1-10, with 10 being the best and 1 being the worst, how well do you think the current system responds to the behavioral health care needs of your community?

Q.35 On a scale of 1-10, with 10 being the best and 1 being the worst, how well do you think the CLTC responds to behavioral health care needs of program participants?

Q.36 What do you think is the most important issue that the state should focus on first to improve access to behavioral health services for you and others?

Q.37 Is there anything else important that you would like to say to CLTC about their program participants' behavioral health needs?

Q.38 That is all I needed to ask you. Do you have any questions? If not, please put None in the blank below. Tell the participant, thank you again. Your answers could help provide quality services to you and others in South Carolina.

Q.39 Interviewer notes

APPENDIX C

KEY STAKEHOLDER SURVEY

History of DMH? Any significant changes in services? Policies? Mandates?
How is our mental health system operated? Public? Private?
Please describe your target population, geographic area served, any mandates and any services you offer related to persons with mental health in SC. Location, priority populations, services offered.
Describe steps your organization has in place to assess and admit people for services. How are they referred to you? Major referral sources.
Data you can provide on number of admissions, length of stay, number of discharges and where consumers are discharged to.
What are major challenges when discharge planning?
What resources are available and what resources are not available but needed for mental health?
How do you educate the public about services available to your organization?
How does your agency collaborate with mental health, substance abuse and/or other agencies to meet the needs of consumers? Is there a process for interagency collaboration? Which agencies participate? Who should be at the table but isn't? Are there opportunities for collaboration?
What are areas of ongoing strengths within the mental health system in SC?
What do you anticipate as possible challenges related to the mental health system?
What are the most critical issues that SC needs to address to meet the mental health needs of its population?
Where do gaps exist in the system and how do these gaps affect the end user? Are there any gaps that are particularly pronounced based on region?
What are the major barriers to accessing services within the mental health system? Geographic isolation, service provider capacity, transportation etc.

Who needs mental health services and does not receive them? What are the consequences of people needing services and not receiving them?
What policy level changes are needed to improve the mental health system at the local, regional and/or state level?